Comily Comily b u l l e t i n Reaching out to Washington families who have children-birth to 6-with disabilities

Recognizing and celebrating the uniqueness and diversity of families



Infant Toddler
Early Intervention
Program

WINTER 2001

Connections on the Journey

By Carla Salldin, Co-Chair Family Leadership Team (FLT)

Hello, my name is Carla Salldin and I am a member of the Family Leadership Team. I have a 4-1/2 year old son who has many medical issues including chronic lung disease, was born at 30 weeks gestation and spent 4-1/2 months in the Neonatal Intensive Care Unit (NICU) before coming home expected to die. We have had many difficult times in the past 4-1/2 years, but there have been many wonderful people helping us in our journey and with many success stories to share.

I have had a lot to learn, including medical, insurance and social service terminology. Asking the right question, in the right way, to the right person, can give you the access to needed services. The most valuable tool that we have is other families. By asking other families questions, they have either a solution or a resource that can send you in the right direction. The Department of Social & Health Services, Division of Developmental Disabilities (DDD), and the Infant Toddler Early Intervention Program (ITEIP) assessed our needs and directed us to programs that suited our family. Our journey took us to a birth to three center, where we worked with excellent staff, received services in the home and at the center and made connections with many parents. Transition to the local school district program at age three has been essential to the continued progress of our son. You should be directed to a Family Resources Coordinator (FRC) early in your journey. The FRC will assist you beginning

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from birth to age three in finding resources for health and developmental services for your child.

We researched information from Children's Hospital Resource Center, our County Department of Health-Children with Special Health Care Needs (CSHCN), our Family Resources Coordinator (FRC), our County Public Health Nurse (PHN), and our Primary Care Physician (PCP). When you have a question, ask one of these resources. You may need to ask more than one resource to get your answer. Do not be shy about asking for support from your community, friends and your family. They do not know how to help you until you are willing to ask for the help and tell them what your needs are.

I am voluntarily involved with the community of Children with Special Health Care Needs. I have been invited to explain the perspective of my family and families like mine. I have met with a U.S. Senator, and been included in medical conferences. I promote medical continuity, empower parents and share my experiences with others. I find this very rewarding and I know that I can make a difference for other families like mine. The Family Leadership Team is a place to make connections and make a difference for other families. We are a growing group of active parents from all across the state. We use E-mail and have telephone conference calls to keep each other current on our team and individual activities. We encourage the exchange of information and are all great supports for one another as we travel on our journey with our children.

Get involved with your child's disability at a level that you are comfortable with. Do not expect that your life has to change and evolve into your identity being replaced by your child's disability. Remember yourself and keep yourself healthy and rested. Treat yourself at least once a month to something that you want to do.

Remember by taking care of yourself, by asking for support from your community, friends and family, you will be strengthening your ability to take the best care of your child.

Greetings Families:

By Sandy Loerch, Director, ITEIP

We hope you enjoyed the first issue of the Family to Family Newsletter. Welcome to the second issue, focusing on Family Support. Why support? Well, who couldn't use some? Most family members need some occasional emotional and informational support. Whether you are a mom, dad, sibling, grandparent, or foster parent, groups are out there to help.

As staff of the Infant Toddler Early Intervention Program (ITEIP), it is our job to support current or future families with infants and toddlers involved in early intervention services. A critical piece is making sure that families are able to get all different kinds of support they may need for their family. It is important to have many kinds of support available, including emotional support.

To meet that goal, ITEIP and the Family Leadership Team (FLT), a committee of the State Interagency Coordinating Council, are involved in two important activities. ITEIP/FLT and the Arc of Washington, via Washington TASH, is working with Washington PAVE, Washington State Parent to Parent, Family Voices of Washington, Washington State Fathers Network, and the Washington State Sibling Support Project to:

- ► Increase, strengthen and further enhance a comprehensive, coordinated, collaborative family support system for Washington families
- ➤ Provide funding to a grant writer to research and pursue additional funding to increase statewide family support activities, and
- ► Hold a family support conference focusing on families with infants and toddlers, ages birth to six with disabilities/delays from diverse, minority and rural areas of the state. This "Family to Family Gathering" was held October, 2000 in Leavenworth, Washington.

These statewide family support groups and organizations have named themselves the Washington Family to Family Network (WFFN).

Greetings to Washington Families

They meet monthly to share information and family support resources, and work to identify the diverse support needs of families. We hope to find improved ways to meet families needs for information and support.

ITEIP funded many specialized activites. For example, we partnered with the University of Washington to promote relationship-focused early intervention and child care services in the state. This activity, supported by research, shows early intervention is effective in enhancing child development when it focuses on promoting positive relationships between caregivers and young children with special needs. This project involved training 20 trainers throughout the state on this model, doing community trainings throughout the state. Two state training conferences were held in September, 2000 to increase parent and professional understanding of what it means to provide quality early intervention services through this model.

ITEIP hopes these activities improve the quality of early intervention services and supports for families who have children with disabilities/delays and special needs. By working and learning together, parents, professionals and community members can improve early intervention services in Washington State. We invite and welcome your participation in local and state activities. Please feel free to contact us at (360) 902-8488, TDD (360) 902-7864 and to visit our Web Site at http://www.wa.gov/dshs/iteip/iteip.html

Washington Parent to Parent

By Julie Ann Avila

Who do you call when you really just need to talk to another family who has a kid like yours? Try your local Parent to Parent (P2P) Program. Washington State Parent to Parent, part of The Arc of Washington State, offers support and provides information to families of children with special needs and/or disabilities. The Arc also maintains a useful website at http://www.arcwa.com. P2P connects parents to a Helping Parent volunteer, another parent, who has a child with similar needs. This can be helpful in coping with challenging experiences and feelings. They can often help with questions and concerns in a personal way.

In addition to emotional support for parents of children with disabilities, P2P offers current information on disabilities, community resources for the child and family, and parent support meetings. Each county program offers different activities to reflect local needs such as training for parents who want to become a helping Parent volunteer, presentations to parent groups, professionals, and other organizations, educational workshops and newsletters. Some P2P programs also have an ethnic outreach program to help offer culturally relevant services. There are 24 Parent to Parent programs across the state.

For information and a map with P2P locations, contact:

Washington State Parent to Parent

Susan Atkins, State Coordinator 10550 Lake City Way NE, Ste. A, Seattle, WA 98125

Telephone: 1-800-821-5927 FAX: 206-364-8140

E-mail: statep2p@earthlink.net

Washington PAVE

Where can parents turn when they want to learn about issues of educational advocacy for their child, birth to 21 years old? Who can

explain what IDEA (Individuals with Disabilities Education Act), IFSP (Individualized Family Service Plan), IEP (Individual Education Program) and ADA (Americans with Disabilities Act) mean? Can you take a class in all of this? The answers are Washington PAVE and yes. Washington PAVE, a parent-directed organization, exists to increase independence, empowerment, and future opportunities for consumers with special needs, their families and communities, through training, information, referral and support. PAVE has six offices across the state, and the majority of PAVE staff are parents who have children with special needs.

PAVE can assist in obtaining early intervention to the age of three and help in understanding the educational system for preschoolers and school-age children. PAVE provides support when you learn your child has a disability or chronic health need, and can help as your child

The Sibling Support Project

Do you ever wonder if the brothers and sisters of your child with special needs are getting their needs met? Are they getting enough attention? Do they have questions about issues of disability or health? Is there enough time between special services and therapy appointments for them to just have fun? The Sibling Support Project (SSP) is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs.

The Sibling Support Project's main goal is to increase the availability of peer support and education programs for brothers and sisters of people with special needs. SSP creates awareness materials such as children's books, websites, and newsletters for siblings, parents, and providers. The Sibling Support Project Newsletter is funny, touching, and informative. We no longer publish our newsletter, but back issues may be found on the website. The website can be reached at http:// www.chmc.org/departmt/sibsupp. It contains an exhaustive list of links to other sites for siblings and about siblings and a great list of books written for children of all ages about specific disabilities. SSP conducts Sibshops, fun filled groups where brothers and sisters have a chance to have fun, learn something new, and support each other. The project also provides technical assistance to those starting a local Sibshop. SSP sponsors listservs for young and adult brothers and sisters. In addition, SSP maintains a database of over 350 existing Sibshops and other sibling programs across the US, Canada, and other international programs. SSP also conducts workshops for parents and providers on the life-long issues facing brothers and sisters. SSP hopes to make programs for brothers and sisters as readily available as Parent-to-Parent programs are for parents.

Don Meyer is the dedicated director of the Washington Sibling Support Project, located at Children's Hospital and Regional Medical Center in Seattle. Don is the father of 4 and married to a special education preschool teacher. He has (co) authored 3 books on sibling related issues. Don was the founder of SEFAM (Supporting Extended Family Members) program at the University of Washington, which helped pioneer support services for fathers, siblings, and grandparents of children with special needs.

CONTACT INFORMATION: Donald Meyer, Director, Sibling Support Project Children's Hospital and Regional Medical Center PO Box 5371, CL-09, Seattle, WA Telephone: 206-527-5712

Fax: 206-527-5705

Starting Point:

Resources for Children with Special Health Care Needs in Washington State

Starting Point is a FREE guide to services and information for Washington State families who have children with special needs. The guide also includes tips from parents on how to get the help you need. We encourage you to make copies of this guide and share it with families and providers. You can find the guide on the Children's website at http://

www.seattlechildrens.org/4_browsers/
parents/special/resource.htm. You can
request a single copy of the guide by
contacting Megan Sety at (206) 527-5709,
extension 1 or msety@chmc.org. The guide
is produced by the Center for Children with
Special Needs and Chronic Health
Conditions at Children's Hospital &
Regional Medical Center.

International Parent to Parent

by Ronda McElroy

As a member of the Washington State Family Leadership Team, I was honored to be given the wonderful opportunity to attend the International Parent to Parent Conference in Reno, Nevada. It was, to me, a phenomenal experience. Over 85 people from various Parent to Parent Networks in Washington attended and Washington State had the largest group.

There were several highlights of my trip: Terry Tafoya's speech on "Hands, Heart and Head Cooperative Approaches to Parenting in a Changing World"; the Parent Portfolio Notebook for Leadership Development that looks at parents' experiences and skills in parenting a child with special needs and other very informative and useful sessions to help our families as well as our communities.

I wear the beautiful silver ribbon given to each of us as a reminder, not only to proudly support people with disabilities, but also to witness the powerful movement in this arena. What I brought back from the conference was a devotion to work together with other parents from across Washington in making a difference here at home.

National and State Resources

Here is a listing of major agencies and organizations concerning children with special needs and their families. There are many resources for disabilities but the ones below can help link you to many other resources.

National Resources:

MAKE A WISH FOUNDATION - National organization that tries to grant wishes to children with terminal illness or progressive disabling conditions. Call at 1-800-304-9474.

FEDERAL INTERAGENCY COORDINATING COUNCIL (FICC) WebSite The FICC involves family members at all levels of policy and service delivery planning. The Family Empowerment Committee recently adopted principles of family involvement as they work at the federal level. For information visit:

www.fed-icc.org/feature.htm

THE FAMILY VILLAGE This is a global community, a vast clearing house, "that integrates information, resources and communication opportunities on the Internet for people with disabilities and their families. Family Village is a must see website at: http://www.familyvillage.wisc.edu/index.htmlx

The National Information Center for Children and Youth with Disabilities (NICHY) This is a national information and referral center that provides information on disabilities and disability-related issues for families, educators and other professionals. This is a good resource for families. You can reach them at their toll free number 1-800-695-0285 or their website http://www.nichy.org/

NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE
SYSTEM (NEC*TAS) NEC*TAS is a national
technical assistance consortium working to
support states and others to improve services
and results for young children with disabilities
and their families. This is a good site to get
information on the Federal Interagency
Coordinating Council. You can access their
website at http://www.nectas.unc.edu

NATIONAL PARENT NETWORK ON DISABILITIES (NPND) Established to provide a presence and national voice for parents of children, youth and adults with special needs. Works to influence and affect policy issues concerning people with disabilities and their families. Contact NPND by phone at 202-463-2299 or go the website http://www.npnd.org/

NATIONAL PARENT INFORMATION NETWORK (NPIN) The National Parent Information Network provides information to parents and those who work with parents to foster the exchange of parenting materials. Their website is http://npin.org

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. (NORD) NORD is the only organization of its kind, a unique federation of more than 140 not for profit voluntary health organizations serving people with rare disorders and disabilities. This organization is dedicated to helping people with rare disorders. Their website is http://www.rarediseases.org/

ZERO TO THREE A national organization dedicated to helping infants, toddlers and their families best navigate the earliest years of life. Their bulletin "Zero to Three" is published six times a year and excerpts are available online. Contact their website at **http://www.zerotothreeorg/** or call (202)-638-1144.

Hot Websites

ABC's of Parenting - an award winning website featuring info on all aspects of parenting. Reach the site at

http://www.abcparenting.com

Parenting Health Resources http://www.ibabydoc.com

For Free Education Publications: I-877-4EDPUBS or www.edu.gov/pubs

Washington Statewide Resources:

Access Washington Resource Directory This is a directory of services for citizens of Washington State. This directory provides access to 22 different types of agencies/organizations for food, clothing, housing, counseling, education, employment, medical, disability and more. Website http://www.awrd.org

Autism Society of Washington - a statewide organization with information about autistic spectrum disorders.

Call (360) 943-2205.

CENTER ON HUMAN DEVELOPMENT & DISABILITY (CHDD) - part of the University Affiliated Program, located at the University of Washington. Has lots of information including current research studies. Call (206) 685-1242.

What's out there?

EPILEPSY FOUNDATION OF WASHINGTON - Information on epilepsy and seizure disorders. Also info on other developmental disabilities and delays. Call 1-800-752-3509.

Family Voices of Washington

Provides information to families on healthcare policy and is part of a national coalition of family members speaking on behalf of children with special health care needs. For more information contact Judie Ebbert Rich at 360-866-8254, email **familyvoices@olywa.net** or check out their great national website:

http//www.familyvoices.org

HEALTHY MOTHERS, HEALTHY BABIES ASK LINE - A telephone resource and referral line with lots of information for families on special needs resources, WIC, breast feeding, nutrition, etc. Call: 1-800-322-2588 or access the website at: http://www.hmhb.org

Prader-Willi Syndrome Association - Information and support on Prader-Willi Syndrome. Call: (206) 285-7679.

RONALD McDonald House - Information on a possible place for parents/families to stay while a child is in the hospital. Call: (509) 624-0500

Sound Options Mediation Training Group - Mediation, negotiation, & conflict resolution training. Call (800) 692-2540

Washington Elks Therapy Program for Children, Inc. - OT/PT therapy services for children not currently receiving services elsewhere. Call (800) 825-3557

Washington Sensory Disabilities Services - Information on blindness, deafness, and deafblindness. Call (800) 572-7000.

Washington Special Education Coalition -Coalition that advocates for special education issues and offers training classes about ADA, IDEA, and IEP's Call (253) 588-0637.

The Washington State Department of Health and Children with Special Health Care Needs

By Leslie Jackson-Carroll Family Consultant, CSHCN Program

"Families are the core of the health services system."

"The community is the center of service provision."

"Systems of care are comprehensive and family centered."

"Systems of care are culturally competent."

These principles guide the work of the Children with Special Health Care Needs Program

Did you know that the Washington State Department of Health has a program that focuses on Children with Special Health Care Needs (CSHCN) ages birth to 18? The CSHCN Program's main office is located in Olympia, but staff work very closely with partners from around the state on a multitude of projects and efforts. The CSHCN Program has a primary focus of promoting an "integrated system of services" for infants and children with or at risk for special health care needs. We partner with families, national, state and local leaders, private and non-profit organizations to identify and act on emerging health issues facing children with special health care needs and their families.

Together with our partners, we provide information and leadership and promote linkages and joint problem solving, to assure that children with special health care needs reach their full potential and have the highest quality of life possible.

In the past year, the CSHCN Program hired a fulltime Family Consultant to work on policy issues related to family support in order to increase family involvement in health policy and program development. Inclusion of families in decision making at all levels is important to the CSHCN Program.

Some of the ways we do this includes:

- Working in partnership with other state agencies, including Medical Assistance Administration (Medicaid), the Department of Social and Health Services, and the Office of the Superintendent of Public Instruction:
- Contracting with and supporting local health jurisdictions throughout Washington to provide care for children with special health care needs (this is done through working closely with Public Health Nurses who are called Children with Special Health Care Needs Coordinators);
- Contracting with and supporting important sources of parent support, including the Washington State
 Parent to Parent organization and the Washington
 State Fathers' Network:
- Contracting with and supporting research and parent support efforts within the University of Washington, Children's Hospital and Regional Medical Center and other health care centers;
- Involving parents in health policy development and program design through the Program's Family Leadership Plan and other related efforts.

Some exciting partnerships currently underway at the Department of Health/Children with Special Health Care Needs Program (in addition to the Parent to Parent and Fathers' Network partnerships) include the Medical Home Partnership and the Child and Adolescent Health Transition Project at the University of Washington, the WorkFirst/Public Health/Children with Special Health Care Needs Initiative; Inclusive Childcare; and a number of other research and family support efforts.

To reach the Children with Special Health Care Needs Program, call 360/236-3571, or email Leslie.Jackson-Carroll@doh.wa.gov

Washington State Fathers Network

Where can a guy go to hang out with other dads who have children with special needs? Where can a father discuss family stress while playing a round of golf? Have you ever seen men discuss how they feel about their children over pizza? The mission of the Washington State Fathers Network (WSFN) is to promote fathers as crucially important people in the lives of their children and families. The WSFN advocates for and provides support and resources for all men and their families who have children with special needs. The WSFN is funded by the Office of Children with Special Health Care Needs, Washington State Department of Health. The WSFN sponsors evening and weekend programs specifically designed for fathers of children with special needs, with fathers serving as facilitators, organizers, speakers, and panelists. Currently there are 14 regional programs throughout the state, from Bellevue to Othello to Spokane, that bring together men for discussion and education, and social events for the family, including potlucks and campouts. The WSFN is also available for 1:1 personal, telephone and e-mail connections.

James May, Project Director, and Lance Morehouse, Father Coordinator, along with a steering committee of dads, are the energetic force behind WSFN. They present at many statewide parent and professional conferences and assist organizations in reviewing their current services to make them "inclusive" of men. The WSFN provides scholarships for fathers to attend conferences, workshops, and activities relevant to their unique concerns. The WSFN also sponsors its own statewide conferences to give men a chance to interact with other dads. Over 100 fathers attended the last conference. The WSFN strives to make many materials available in both English and Spanish. "Connections", a father-driven newsletter, is produced three times a year, and the stories are heart touching, personal, and told from a male perspective.

The WSFN also maintains a superb web site filled with extensive family resources. photos, and articles for both families and providers. The links are wonderful, with sites

for fathers, disabilities information, families, health care, legal issues, and Washington State. Two of my favorite sites are entitled Boot Camp for New Dads and Slowlane - Stay At Home Dads. Check it out at:

http://www.fathersnetwork.org

CONTACT INFORMATION:

Washington State Fathers Network (WSFN) 16120 N.E. Eighth Ave., Bellevue, WA 98008-3937 Attention: James May, Project Director Telephone: 425-747-4004 (ext. 218)

or 206-284-2859

Fax: 425-747-1069 or 206-284-9664

e-mail:

James May: jmay@fathersnetwork or Lance Morehouse: Fathersnet@aol.com

Interagency **Coordinating** Council (ICC)

National Parent Leadership Support Project

This is a leadership support project for parents of children with disabilities serving on Interagency Coordinating Councils.

Purpose

The National Interagency Coordinating Council Parent Leadership Support Project is designed to help parent leaders serving on Interagency Coordinating Councils throughout the country. These parent leaders play a critical role in developing policies and designing programs for young children with disabilities and their families.

The goal is to learn from and support parents serving on ICC's throughout the country by providing access to resources and communication networks vital to their work.

FOR INFORMATION WRITE, CALL, OR VISIT AT:

National ICC Parent Leadership Support Project Federation for Children with Special Needs 1135 Tremont St. Suite 420 Boston, MA 02120

Toll-free number: (800) 493-2338 x 211 Website address: www.iccparent.org

Washington PAVE CONTINUED FROM PAGE 2

transitions from school to adult life. PAVE offers workshops on many subjects including special education, transition, cultural diversity, family centered care, birth to three, military issues, communication skills, etc. PAVE maintains a lending library with books, audiotapes and videotapes. PAVE has information about resources and specialists in your community, starting parent support groups, and finding existing support groups. PAVE also has volunteers in many local communities to support parents as they learn about the systems that provide services to their child with special needs.

One project of PAVE is STOMP (Specialized Training of Military Parents). STOMP provides information and training on military and other regulations affecting special education for military parents worldwide through workshops, phone consultation and presentations. STOMP also maintains a list of on-line resources relevant to families in the military. Another project of PAVE is the Parent Participation Coordination Project for the Infant Toddler Early Intervention Program which provides technical assistance, training, and information regarding IDEA and early intervention services to parents, families, state agencies, contractors and others interested in family-centered services.

PAVE maintains a wonderful website at http://www.washingtonpave.org. It contains information on upcoming workshops and events, access to the highly informative newsletter (PAVE Pipeline), a discussion board, chat room opportunities, links and resources,

Continued on back page

PLEASE SEND ALL NEWSLETTER CORRESPONDENCE TO THE ATTENTION OF: Cassie Johnston, PAVE

6316 S. 12th Street, Tacoma, WA 98465 or FAX (360) 902-8497 e mail: weccare@olywa.net

Family to Family Bulletin is produced by the Family Leadership Team which is a standing committee of the Washington State Infant Toddler Early Intervention Program's (ITEIP) State Interagency Coordinating Council (SICC). ■ The mission of the Family Leadership Team is that families are represented at all levels of the state's early intervention system for children with developmental delays, age birth to six. ■ The mission of ITEIP is to work with Tribes, state agencies, & local communities to assure that all eligible infants & toddlers (birth to 3 years old) with disabilities/ delays & their families in Washington State have access to individualized, quality early intervention services in accordance with the Individuals with Disabilities Education Act (IDEA), Part C.

Editorial Board Members: Sandra Lund, Gigi Igama, Cassie Johnston, Karen Lindsay, Sandy Loerch & Ginger Kwan. Correspondent-at-large: Julie Ann Avila

Staff: Kathy Blodgett.

Washington PAVE CONTINUED FROM PAGE 5

and a great section with answers to frequently asked questions about the special education process. One strength of the website is the access to a broad array of links and resources that cross all disability categories, regions, and age groups.

CONTACT INFORMATION:

Washington PAVE (Main Office) 6316 So. 12th St., Tacoma, WA 98465

Telephone: 1-800-5-PARENT Fax: 253-566-8052

E-mail: wapave9@washingtonpave.com



Family
Leadership
Team (FLT)
Summer
Meeting
and Potluck
August, 2000
Miller Park
Yakima,
Washington

Children's Therapy Center of Kent

The Children's Therapy Center (CTC) of Kent wishes to pass on to the readers that they strongly encourage families to participate in their services, and work to give families tools and techniques to better meet the developmental needs of their child. CTC reports that they have never had a waiting list and that they are committed to find the time and therapist that will meet the individual needs of each family and child. Siblings are accommodated and encouraged to participate. Many families receive home visits and many more receive a combination of home, community and center-based services. CTC feels that early intervention programs should address the needs and abilities of the whole family; child, siblings and parents. Thanks CTC for sharing information about your program.

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Washington PAVE 6316 S 12th Street, Tacoma, WA 98465

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